



pacds

Parent Assistance Committee on Down Syndrome
A volunteer arm of Westchester Arc

235 Albemarle Avenue
White Plains, NY 10605

Summer 2008

UPCOMING EVENTS

July 11-13, 2008

NDSC Annual Convention in Boston. See page 5

July 16, 2008

Parent/Child group picnic at Gedney Park in Millwood. Call Kathy Higgins 347-3227 x107

August 20, 2008

Parent/Child group swim party at Birchwood Swim Club in Chappaqua. Call Kathy Higgins 347-3227 x107

August 10, 2008

Annual picnic at Downing Park in Yorktown Heights

Sept 28, 2008

NDSS Buddy Walk in Central Park. See pg 6 for details

Oct 15-19, 2008

NYS Arc Convention in Albany. Details to follow.

October 21, 2008

Westchester Arc's Annual "Matter of Taste" Event in Rye See pg 4 for details

The 35th Annual PACDS FAMILY PICNIC

**SUNDAY, AUGUST 10th At NOON
At John Downing Park in Yorktown**

Please come join us for an afternoon of fun, renew old friendships, make new friends, and have a great time. Bring your whole family! There will be carnival games, face painting, food and fun. **And don't forget to bring your mitts if you want to play some softball!**

We will again post a board for pictures so please bring some to share. As usual, please also bring food for the buffet- **a main dish, salad or dessert**. We'll provide the grill food, drinks & paper goods. **We are asking for a suggested donation of \$10 per family to help cover the rental of the park's pavilion, the grill food, etc.**

Directions: Take the Taconic Parkway to the Rt. 35/202 exit

- At the light, turn east onto 35/202

- John Downing Park is ½ mile ahead on the right

RSVP: Please let us know how many people are coming with you and what food you are bringing. Also, we need helpers for that day, so let us know if you can help out. Contacts are: Stephanie Bellantoni (914-761-3185) and Patti Conte (914-654-0238)

SEEKING NEW MEMBERS

PACDS needs spirited new committee members. NO EXPERIENCE NECESSARY! We need help to continue to provide support and programming for our families. For our organization to continue to provide assistance, education, and support we need you! Our next meeting is Sunday, June 22, 2008, at 7 pm at Caroline Furry's house in White Plains. If you are interested in getting involved and/or joining the steering committee please contact Caroline at 949-3948 or dfurrywitt@netzero.com.

PARENT / CHILD
PLAYGROUP

For kids birth to 5yo. This group is held at and run by the Children's School for Early Development in Hawthorne, in collaboration with PACDS

Future dates are not yet set for the fall - check the next newsletter for details.

Groups meet from 930am-11am. For info contact: Kathy Higgins at the Children's School at 347-3227 x107

ELEMENTARY AGE
PLAYGROUP

This group has been meeting monthly for years and welcomes new members.

For details call Margaret Lewis at 235-9527

GIRL IN UK TO GET COSMETIC SURGERY

The parents of a girl with Down syndrome have caused a public outcry in the U.K. by subjecting their daughter to cosmetic surgery to improve her appearance.

Georgia Bussey underwent "radical and painful" cosmetic surgery three times by age 5 so she could "fit in" with her peers, the U.K.'s Daily Mail reports.

Parents of another girl with Down syndrome told the paper that they were also considering altering her appearance in the future so she could be more "accepted."

Critics in the U.K. slammed the parents, with some even claiming the procedures were tantamount to child abuse. However, the parents hit back, saying that no one complained when "normal" children had their ears pinned back.

"Why should it be any different for a Downs child?" asked Georgia's mother Kim Bussey.

Bussey said she and her husband David were motivated by love for their child and deliberated for a year before putting her through the ordeal.

In the first procedure, Georgia's tongue was reduced to stop it from protruding, according to the paper. Then folds of skin were removed from the inner corners of her eyes to take away the "slantiness characteristic" of Down syndrome. Finally, she had surgery to stop her ears from sticking out.

Bussey said society often judges people on the way they look.

"Society is not going to change overnight - so Georgia has to fit into society, rather than society fitting into the way she is," she said.

Another couple, Laurence and Chelsea Kirwan, told the newspaper they were considering surgical procedures for their two-year-old daughter Ophelia, who has Down syndrome.

Dr. Laurence Kirwan, a world-renowned plastic surgeon with offices in the U.K. and Connecticut, said they would make that decision if Ophelia reached the age of 18 and was being unfairly judged on how she looked.

PACDS CONTACTS

Co-Chairpersons:

Rosa Sanchez
293-0130
Caroline Furry
949-3948
Terri Hunt 243-5874

New Parent

Contacts:
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Patty Conte
654-0238

Newsletter:

Ivy Lewis
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Parent/ Child Group:

Terri Hunt
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Elem. Playgroup:

Margaret Lewis
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Teenage Contacts:

Jean Corvino
693-5392
Magaly Olivero
949-2594

Adult Social Group:

Barbara Albrecht
(845) 628-8972
Debbie Eiseman
(718) 884-8496

Family Picnic:

Stephanie
Bellantoni
761-3185 and Patty
Conte 654-0238

PACDS Hotline:

739-4085

Spanish Liaison:

Rosa Sanchez
293-0130

AK GOVERNOR HAS BABY WITH DOWN SYNDROME

On April 18, 2008, Sarah Palin, the first term governor for Alaska, gave birth to her fifth child, Trig Paxon Van Palin. Trig has Down Syndrome and Ms. Palin had found that out when she was four months pregnant due to prenatal testing. When she went to her office three days after Trig was born, it was not just to show off her new baby, it was to let everyone know that a child of special needs would not hinder her professional commitments. "It's a sign of the times to be able to do this ... there is no reason to believe a woman can't do it (this job) with a growing family ... my baby will not at all or in any sense be neglected". Palin says she has taken strength from another politician who has walked in her shoes, U.S. Rep. Cathy McMorris from Washington, whose son Cole just celebrated his first birthday. McMorris says "It's in human nature to focus on the negative, on what the person can't do. In our mind, we are focused on what he can do, what he will be able to do and do very well".

DOWN SYNDROME DOLLS

The Pattycake Doll Company takes great pride in making dolls that celebrate special needs children and their extra large capacity for love. They offer a Down Syndrome Doll, either a girl or a boy, that is 14 inches high and made of lightweight cloth, in both white and ethnic skin tones. Children with Down syndrome can finally say "my doll looks like me". They also offer dolls that help with color identification, fine motor skills, etc., as well as a doll wheelchair for those that are non-ambulatory. Visit their website www.pattycakedoll.com to see all their products.

ALZHEIMER DRUG MAY HELP OUR KIDS

Drug makers Eisai and Pfizer believe their Alzheimer drug Aricept may help children with Down syndrome. Aricept has been used by older people for more than a decade, but now a study is underway in Western Washington to see if it can also help youngsters. Psychiatrist Dr. Arif Khan is heading up the study at Bellevue Hospital, enrolling children with Down syndrome between the ages of 10 and 17. People with Down syndrome often develop Alzheimer's disease decades earlier than others and Khan thinks that Aricept could make these children "more verbal, be able to solve problems much better, be more independent, not be as dependent on the family". The study has children taking either Aricept or a placebo for 10 weeks to see if there is a difference in their abilities.

WEBSITES OF INTEREST:

Below are some websites that may be helpful in your search for information.

www.ndss.org
National Down Syndrome Society

www.ndsccenter.org
National Down Syndrome Congress

www.downsed.org
British website with extensive information

www.ds-health.com
Dr. Len Leshin, pediatrician and father of a child with DS. Articles and links to other websites. Of particular note: healthcare guidelines and growth charts.

www.metlife.com
financial planning for children with special needs.

www.woodbinehouse.com
Publishers featuring a special needs collection including many titles specific to Down syndrome.

[A MATTER OF TASTE](#)

Westchester Arc hosts "A Matter of Taste" every year - the event allows you to sample signature dishes from the finest restaurants in the area, paired with terrific wines from around the world. The event will be held October 21, 2008 at the Westchester Country Club in Rye, NY. See www.westchesterarc.org for details.

[FREE WORKSHOP IN THE BRONX](#)

Resources for Children with Special Needs, Inc. holds FREE workshops for families with children, youth and young adults with disabilities throughout the school year. There is one more program this year, on June 20, 2008 entitled "Getting Appropriate Educational Services". The program runs from 10am-1pm. Refreshments will be served, but there is NO child care available. Gary Shulman is the Training Coordinator for this group and can be reached at 212-677-4650 x20 if you have questions about this program. It is taking place at the Visiting Nurse Service of New York, 489-493 East 153rd Street.

[CHECK OUT THE MIRACLE LEAGUE:](#)

If you are looking for a way for your child with Down syndrome to play baseball, and your own school district does not have an appropriate program, come check out the Miracle League, at www.mlwny.org or 914-960-6391.

The Miracle League is a national organization founded in Atlanta in the mid-1990s, which believes "every child deserves a chance to play baseball". There are more than 140 Miracle League fields throughout the US, including one in Hartsdale, NY at Ridge Road Park. Miracle League participants play on a specially designed rubberized field which is completely flat (the lines and markings are painted on), allowing for both ambulatory and non-ambulatory children to play without restrictions. The Miracle League plays several games on Saturdays and several games on Sundays, in both the spring and the fall, so it's easy to pick a convenient time, and each player is matched with a buddy who is either a teenager or an adult. Each game lasts about two hours, but there is no scoring, resulting in only winners in each game.

Several PACDS members play with the Miracle League and agree it's a wonderful organization that goes out of its way to make sure every child, whether they are high functioning, low functioning or anywhere between, has a great time playing baseball. And it's free!

www.hwtears.com
Tips, materials and seminars focusing on pre-printing, printing and cursive writing as per the Handwriting Without Tears Program.

www.talktoolstm.com
Sara Rosenfeld-Johnson site for seminars and speech tools (e.g. straw hierarchy, horns)

36th ANNUAL NDSC CONVENTION:

Hosted by the National Down Syndrome Congress
July 11-13, 2008 at the Boston's Seaport Hotel
800-385-4000 or www.seaportboston.com
Ask for rooms in the NDSC block

This is a conference for parents, professionals, siblings, teens and adults with Down syndrome. There is something for everyone. Visit www.ndsccenter.org for more information on this convention.

YANKEE STADIUM DISABILITY AWARENESS NIGHT

On July 31 the Yankees are hosting Disability Awareness Night on behalf of Exceptional Parent Magazine and Mass Mutual. There are almost 20 of these nights throughout the US, continually raising awareness of the 54 million Americans living with disabilities. Check out EP's website for details, www.eparent.com.

COME SAIL ON THE BUDDY CRUISE

FRIENDS-Support, Inc is presenting an exclusive Down syndrome awareness cruise on board Royal Caribbean Cruise Lines "Sovereign of the Seas". This 3 night Bahamian cruise departs Port Canaveral, Florida on October 17, 2008. FRIENDS-Support, Inc is using this Buddy Cruise as a way for families from all across America to come together and bring awareness to Down syndrome.

Sujeet Desai will be featured on the Cruise – Sujeet is a 26 year old musician with Down syndrome. He and his wife Carrie have been featured on The View, 20/20 and Oprah. Sujeet will share his musical talents with his fellow cruisers and will also share his story from birth to marriage, including his graduation from the music academy and the NY State funded program that helps he and his wife remain independent.

PACDS member Emily Kingsley will be presenting the Keynote Presentation "Thirty Four Years with Down Syndrome. The 'ups', the 'downs' and what I've learned from life with Jason" (her son). Emily has received 17 Emmy Awards and 13 Emmy nominations for her work on Sesame Street, specifically her efforts to include people with disabilities in the cast. She will also present two workshops and her son Jason will present a workshop as well.

Nikole Whitehead, co-founder of STAND (www.STANDAdvocates.org) will also be giving a presentation on the Buddy Cruise called "Cruising Through Your Child's Special Education".

Reservations for the Buddy Cruise can be made through Cruise Planners at 1-888-464-1827.

HEAR YE!

HEAR YE!

Get all the news as fast as it's out!
Send your email address to Anne Majsak to be included in the PACDS email chain
amajsak@verizon.net

NEW RESEARCH

New work in mice suggests that one gene on the 21st chromosome is a major contributor to Down syndrome's learning impairment. If that's so, researchers might be able to come up with a treatment regimen that would target the one gene. Dr. William Mobley of Stanford University, who is spearheading the study, says "it's really possible that beginning with a specific abnormality you can chase it down – if not to one gene only, then to one gene that plays a major role ... and now you can think about therapies which you couldn't really do before". Roger Kafker, a cofounder of the Down Syndrome Research and Treatment Foundation, which helped fund Mobley's study, predicts that this progress might eventually lead to the ability to bring children with Down syndrome up to normal intelligence. The gene called "App" instructs the body to make amyloid precursor protein, and having three #21 chromosomes produces an extra App gene which produces extra protein. Researchers have found that the extra amyloid protein appears to block a key communication process from neuron to neuron, a message that tells a neuron to "be well, stay alive". With that message blocked, certain neurons that are important for learning and memory shrivel up. Mobley's research is studying the effect of extra amyloid protein on mice and they have seen that the more App a mouse had, the more the communication was blocked. David Patterson, who is a Down syndrome researcher at the University of Denver that was not involved in the study, says "this is not the only thing that causes trouble ... but what they have done here is gives us some really good ideas and really good targets to pursue".

NATIONAL DOWN SYNDROME SOCIETY BUDDY WALK

This year is NDSS's 14th annual Buddy Walk. It takes place this year on Sunday September 28, starting at noon at the Great Hill in Central Park. The Buddy Walk promotes acceptance and inclusion of individuals with Down syndrome.

Prior to the Walk, starting at 1030am that morning, a video will be shown on the Panasonic News Corporation's Astrovision screen in Times Square. A Video Contest is being held for selection of photos for the video. In you would like to submit a photo for consideration, contact Becky at NDSS via phone at 877-526-0270 or via email at timessquarevideo@ndss.org. The deadline for photo submission is July 18, 2008.

See www.buddywalk.org for details on the Buddy Walk.

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